

# Information needs, preferred educational messages and channel of delivery, and opinion on strategies to promote organ donation: a multicultural perspective

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## ABSTRACT

**Introduction:** This study assessed the information needs, preferred educational messages and channels of delivery, as well as opinions on strategies to promote organ donation. It aimed to provide insight into a culturally sensitive public education campaign to encourage organ donation in diverse ethnic communities in Asia, namely the Malays, Chinese and Indians.

**Methods:** A total of 17 focus group discussions with 105 participants were conducted between September and December 2008. The participants were members of the general public aged 18 to 60 years, who were recruited through convenient sampling in the Klang Valley area of Malaysia.

**Results:** Across ethnic groups, there was a general concern about the mistreatment of the deceased's body in the organ procurement process. The Chinese and Indian participants wanted assurance that the body would be treated with respect and care. The Muslims wanted assurance that the handling of a Muslim's body would follow the rules and regulations of the Islamic faith. The most important information requested by the Muslim participants was whether cadaveric donation is permissible in Islam. A lack of national public education and promotion of organ donation was noted. All the three ethnic groups, especially the Malays, required community and religious leaders for support, encouragement and involvement, as sociocultural influences play a significant role in the willingness to donate organs.

**Conclusion:** The pronounced ethnic differences in information needs suggest that culturally sensitive public educational messages are required. Organ donation and transplantation organisations should work closely with community and religious

organisations to address the sociocultural barriers identified.

**Keywords:** channel delivery, educational messages, information needs, multicultural, organ donation

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## INTRODUCTION

Asians living in Asia as well as in Western countries have among the lowest rates of organ donation in the world.<sup>(1,2)</sup> Malaysia is an Islamic country with a majority Muslim Malay population, but it also comprises people from other ethnicities, mainly the Chinese and Indians, along with other minority ethnic groups. The Chinese are predominantly followers of Buddhism, Taoism and Confucianism, and the majority of Indian Malaysians are Hindus or Sikhs.<sup>(3)</sup> There have been many reports about the religious and traditional cultural beliefs that contradict the tenets of organ donation among Muslims,<sup>(4-8)</sup> as well as among people of Chinese<sup>(9-11)</sup> and Indian<sup>(12,13)</sup> origin worldwide. Malaysia has a voluntary system of cadaveric donation. Individuals opt in by signing a donor card, or by contacting the National Donor Registry. As the three main ethnic groups are those with the most pronounced cultural and religious prohibitions against organ donation, the shortage of organ donations poses a great challenge to the Malaysian health care system.

European countries have a mean of 15 donors per million population. Spain has by far the highest organ donation rate in the world, with 31.5 donations per million population. Organ donation rates per million are low in Latin America and Saudi Arabia, which have a rate of 2–4 donations per million population.<sup>(14)</sup> The rate of organ procurement (per million population) in Malaysia was only 0.53 in 2005, and increased to 1.01 in 2006.<sup>(15)</sup> Although there has been a steady increase in cadaveric organ and tissue donations in Malaysia over the years, its rate is still among the lowest in the world and among Muslim countries. For instance, between

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1997 and 2006, only 162 organ procurements were carried out in Malaysia.<sup>(15)</sup>

Many studies have been conducted worldwide to elucidate the public's perceptions and responses to human organ donation and transplant. On the whole, Asians are more reluctant to donate organs compared to Westerners.<sup>(1,2)</sup> We conducted a qualitative study to assess the public's knowledge and attitudes with regard to cadaveric organ donation and transplantation across the three main ethnic population groups in Malaysia.<sup>(16)</sup> In keeping with the findings of other such Asian studies,<sup>(5,6)</sup> our study found a diversity of barriers, including perceived religious prohibition, cultural myths, a fear of disfigurement and surgical procedures and a distrust of the medical system.

This paper presents the second part of the findings of our previous study,<sup>(16)</sup> through which we aimed to identify the areas of educational needs and to provide insight into how to generate a culturally sensitive public education campaign that is suited to the diverse ethnic communities. The qualitative method of research was adopted because of its many benefits in this context. For example, it can provide in-depth understanding of a variety of complex matters and explore the wide range of concerns surrounding organ and tissue donation in our multiethnic community.

## METHODS

Data was collected in focus group discussions (FGDs) with multiethnic Malaysians. A convenient sample of members of the general public aged 18–60 years was recruited from the Klang Valley area of Malaysia. A discussion guide consisting of a series of questions and prompts was designed so as to direct the discussion to correspond with the research questions. The guide schedule focused on: (1) the information that participants require in order to decide whether to donate their organs after death; (2) their preferred public educational messages and channels of delivery of these messages; and (3) their opinion on strategies to promote organ donation. The guide was pilot-tested and revised, and the final version was used for all the focus groups.

In order to allow for cross-group comparisons, the focus group participants were grouped based on ethnicity (Malay, Chinese or Indian). Group discussions were conducted in English, Bahasa Malaysia (the Malaysian national language) or the respondents' native language (Cantonese or Mandarin). Discussions were conducted for approximately one hour each, and were audiotaped and transcribed into English. All the focus groups were moderated by a sole researcher. Notes taken

**Table 1. Characteristics of the focus group participants (n = 105).**

Characteristic	No. (%)
<b>Gender</b>	
Male	47 (44.8)
Female	58 (55.2)
<b>Age (yrs)</b>	
< 30	61 (58.1)
30–49	26 (24.8)
≥ 50	18 (17.1)
<b>Ethnicity</b>	
Malay	47 (44.8)
Chinese	36 (34.3)
Indian	22 (20.1)
<b>Religion*</b>	
Muslim	47 (45.2)
Buddhist	22 (21.2)
Taoist	5 (4.8)
Hindu	20 (19.2)
Christian	10 (9.6)
<b>Highest educational attainment</b>	
Primary	6 (5.7)
Secondary	45 (42.9)
College/University	54 (51.4)
<b>Occupation</b>	
Professional	8 (7.6)
Managerial	12 (11.4)
Skilled worker	41 (39.0)
Unskilled worker	1 (1.0)
Housewife	19 (18.1)
Student	17 (16.2)
Unemployed/retired	7 (6.7)
<b>Average household income†</b>	
< RM2,000	36 (34.3)
RM2,000–RM4,000	43 (41.0)
> RM4,000	26 (24.8)
<b>Locality</b>	
Urban	81 (77.1)
Rural	24 (22.9)
<b>Registered as organ donor</b>	
Yes	4 (3.8)
No	101 (96.2)

\* Data was missing for one participant.

† US\$1 = Malaysian Ringgit (RM) 3.51, as of August 12, 2009.

All values are based on the participants' self-reporting.

by the moderator and note-taker were supplemented with the audiotapes in order to glean the details of the discussions. Data from the focus groups was analysed in a descriptive and interpretive manner. Coding began by identifying broad conceptual themes and grouping them into major categories and subcategories. Phrases and quotations that highlighted the themes were identified. Coding was performed by a single coder, and the consistency of coding was assessed by intraobserver reliability, where the same data was coded at various points in time and the agreement percentage was calculated. The calculated intra-rater agreement was in the 90th percentile range. This study was approved

by the Medical Ethics Committee, University Malaya Medical Centre, Kuala Lumpur, Malaysia.

## RESULTS

The FGDs were held between September and December 2008 at locations and times that were convenient for the participants. A total of 17 FGDs were conducted, with five to eight Malaysians in each FGD (total of 105 participants). There were seven Malay, six Chinese, and four Indian focus groups. Only four participants indicated that they had registered to be organ donors. Table I presents the demographic distribution of the study sample.

Table II provides a summary of the emergent themes with illustrative quotes from participants in response to the questions asked during the discussions. Most of the Hindu and Buddhist participants stated that their religion supports and encourages organ donations. Only a minority of Hindu participants expressed the belief that organ donation is against their religion. The religious aspects of organ donation and transplantation were brought up and most often debated upon by the Muslim participants. The most important information required by Muslim participants pertained to whether cadaveric donation is permissible in Islam.

Across ethnic groups, there was a general concern about the mistreatment of the deceased's body in the organ procurement process. The Chinese and Hindu participants wanted assurance that the body would be treated with respect and care. The Muslim participants wanted assurance that the handling of the body of a Muslim would follow the rules and regulations of the Islamic faith. The participants in this study suggested that culturally sensitive messages about organ donation are required in the multiethnic Malaysian community. They also viewed that the involvement of community and religious authorities in education and in the dissemination of information is required to eliminate sociocultural misconceptions and perceived religious objections to organ donation. Among the three ethnic groups, the need for support and encouragement from their religious leaders in information dissemination was most commonly cited by the Malay participants. They reasoned that religious influences play a significant role in their willingness to donate organs.

Regardless of ethnicity, many participants felt that featuring the stories of potential organ recipients and family members of cadaveric organ donors was the most effective way to draw public attention to the issue. Many urged the authorities to exert more effort in scaling up organ donation promotion. They expressed the view that

an intensive public education campaign about organ donation through multi-channel delivery methods is highly warranted. Some participants suggested having registration kiosks at workplaces, in public places like shopping centres, or in busy areas such as bus and train stations, to increase opportunities to sign up for organ donation. There were also suggestions to implement an online registration system. When asked about strategies to promote organ donation, the lack of a promotion and awareness campaign was again brought up by the participants during the discussion. They felt that if organ donation is a commonly occurring action, more people would be willing to donate their organs.

All the three ethnic groups, especially the Malays, expressed the need for the involvement, support and encouragement of community and religious leaders. Many expressed the opinion that insufficient promotion of and information pertaining to organ donation was made available to the general public, and urged the authorities to play a more proactive role. A small minority of participants opined that the National Donor Registry should provide feedback to those who have registered as organ donors, which would give them a sense of connection with the registry.

## DISCUSSION

Sociocultural influences on the willingness to donate organs have been reported in many Asian countries.<sup>(5,17-19)</sup> They have also been shown to play a significant role in this study. Malaysians generally have a strong sense of religious traditions and cultural norms. It is thus important to recognise the pronounced ethnic differences in values, attitudes and beliefs with respect to organ donation. In particular, the Muslim participants' responses in our study reveal the strong influence that religious beliefs exert as a foundation for attitudes toward organ donation. As reported in other studies,<sup>(3,6)</sup> our study found that perceived religious objections act as a major barrier to organ donation among the Muslim participants. Nevertheless, it is important to note that not all our Muslim participants had negative attitudes toward organ donation. A considerable number of them supported organ donation but were unsure if it is permissible for Muslims. The information that Muslim participants identified as most needed was the organ donation and transplantation ruling in Islam. This has also been found to be the case in other studies.<sup>(3,17)</sup> These findings indicate that religious leaders play an important role in clarifying whether cadaveric organ donation is permissible in Islam. It is therefore essential for them to come up with fatwa, or religious rulings, on organ donation.

**Table II. Summary of emergent themes and selected quotes.**

Theme	Quotes
<b>Information needs</b>	
Religious aspects of organ donation	<p>"It is stated in Islam, mutilation of deceased body is prohibited. We don't know whether organ donation is permitted, because donation will mutilate the body. We need clear rulings from religious leaders." Malay female, 28</p> <p>"We want opinion from ulamas (religious leaders), whether we can give to non-Muslim. It's very important to us, the ulama's opinion." Malay female, 40</p>
Treatment of the deceased's body	<p>"We want to know how the operation is done on dead body. Scared if the doctors chop recklessly and mess up the body, or perhaps get a medical student to do." Chinese female, 43</p> <p>We want to know whether the deceased's body is subjected to disrespectful treatment, specifically no facial disfigurement." Indian male, 28</p> <p>"Are there rules for the proper handling a deceased Muslim, in each steps of organ procurement up to washing and shrouding after procurement?" Malay female, 40</p>
<b>Educational messages and channels for transmitting information</b>	
Religious authorities	<p>"...so far no official effort on the religion side. The religious leaders play important role, they can talk about organ donation in Khutbah Jumaat (Friday sermon)." Malay male, 29</p> <p>"Provide information through religious authorities in rural areas because they are conservatives." Malay male, 19</p>
Campaign via mass media	<p>"The influence of movie is huge, it will draw people to donate." Indian male, 28</p> <p>"More heart-warming stories of people who need organs in newspapers, TV." Malay male, 56</p> <p>"Show the statistic of organ pleaders, and very few people donate, then the public know it is critical." Chinese male, 34</p> <p>"Testimonies from registered donor, from people who need organs, family members of the deceased organ donors, and the organ recipients...tell us how it changed their lives." Chinese female, 57</p>
Multi-channel delivery	<p>"For those highly educated, can have promotion at workplace, or public places like shopping centres. Not restricted to only in hospitals." Chinese female, 21</p> <p>"That time, I saw the booth, I just signed up. Up till now, I have never seen any again. Have to be active, more outlets for people to register." Indian female, 30</p>
<b>Strategies to promote organ donation</b>	
Easy registration	<p>"No need to go to KL (Kuala Lumpur), if can register in our local district clinic, people can easily drop by." Malay female, 38</p>
Social norms of organ donation	<p>"More campaigns and promotions. Just like blood donation campaigns, you can see almost everywhere and very frequently. 10 or 20 years back, our people were afraid of donating blood, but now it is like a norm." Indian male, 24</p>
Involvement of religious and community leaders	<p>"The imams (prayers leaders) and ketua kampung (village heads) leader should have awareness first, because most of us are conservative. We hardly hear anything about organ donation here." Malay female, 29</p> <p>"Preferable give Muslim an option, if they (donor) Muslim, strictly Muslim recipients. They are potential donor and willing to donate." Malay female, 27</p>
Others	<p>"I have registered, but it is like nothing...no support or news from them. I donate for WWF, they give us bulletins...in the bulletins they will state their current projects, updates... and how the progress like...you know...send you a card wishing you happy birthday. Even Jusco (hypermarket) membership they send you cards and updates. It's like...they aware your existence. But for organ donor, it is ... quiet. I don't know if my name is still in the list. At least they should have bulletins to update us, show us the current statistics of donor or procurement and person in need of organs. Or a website, display of registered donors list, people donated organs or recipients. I would be proud if I see my name there." Malay female, 29</p> <p>"The donor card is a paper card, I used to keep in my wallet, but over time, it is already hancur (damage). It should be like our IC (identity card), durable. No effort to ask us (registered donors) whether we still constantly carrying the card, or do we need a replacement card." Malay male, 29</p>

Given the high level of concern across all the ethnic groups regarding the mistreatment of the deceased's body in the organ procurement process, information on the proper treatment of the body should be emphasised to the public. Awareness and education about organ donation needs to be enhanced through mainstream mass media. In terms of strategies to promote organ donation, there is a need for multi-channel organ donation request approaches so that the issue of organ donation would become a widely known social norm in the community. Our Muslim participants expressed a desire for the involvement of religious leaders in organ donation awareness and education; organ donation promotion activities should therefore involve religious leaders and may best be incorporated into mosque activities.

The National Donor Registry should play a more proactive role in providing ways of contacting and staying in touch with people on the organ donor registry in order to make donors feel appreciated. For the Chinese and Indians, it is essential to obtain encouragement and motivation from their respective community leaders. It has been reported that when religious leaders are in favour of organ donation, the community is more likely to donate,<sup>(20)</sup> and this support from religious groups is an important factor in overcoming barriers to organ donation.<sup>(21)</sup> Most importantly, our participants urged organ donation and transplantation organisations to take proactive measures to increase public awareness of the critical need for organ donation.

The results of this study must be interpreted within the context of the qualitative research design. Caution must be exercised in drawing conclusions beyond the sample of the present study, and causal inferences cannot be established. Another limitation of the study was the use of a convenience sample. However, the demographics of the participating population are similar to those of the general population, suggesting that these results may be reflective of national trends. Despite this methodological caveat, the issues highlighted in this study are of considerable importance in designing organ donation communication, educational and promotional campaigns in multiethnic societies.

In conclusion, the major implication of this study is that educational information on organ donation has to be delivered in a religiously and culturally competent manner to all ethnic groups in multiethnic populations. Additionally, the religious and cultural beliefs of all ethnic groups must be considered in organ donation education and communication in order to gain community acceptance. This is particularly important

for Muslims, as their beliefs and behaviour toward organ donation is strongly influenced by religious norms. Therefore, community and religious authorities should be involved in the education and dissemination of information that eliminates barriers to organ donation among the Muslims. Organ donation and procurement organisations should proactively organise more public promotion and awareness education programmes. Apart from actively encouraging the public to sign up to be potential organ donors, efforts to make people on the organ donor registry feel connected to the organisation are essential. The information obtained from this study will aid future initiatives to increase organ donation in our society and in other communities with multiethnic populations. The findings suggest the need for an integrated approach to enhance organ donation in countries with multicultural and multiethnic societies. The findings also provide insight into culturally sensitive organ and tissue donation communication activities that would help increase the rate of organ donation in a diverse ethnic community.

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